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The Experiences of Nurses Caring for Patients with Neurogenic Bowel Dysfunction in the Acute Setting

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12 Abstract

13 Study design: Qualitative.

14 Objectives: Explore the lived experience of nurses providing bowel care to patients after Spinal
15 Cord Injury (SCI).

16 Setting: UK NHS Acute Care Hospital and Major Trauma Centre.

17 Methods: Semi-structured interviews with 11 registered nurses were undertaken to explore their
18 experiences of providing bowel care.

19 Results: Four major themes emerged: Unpleasantness of task; perceived patient experience;
20 motivation and avoidance; and barriers to care. There was stoic acceptance of the unpleasant
21 nature of bowel care for the nurse but unpleasantness for patient wasn't so readily accepted.
22 Perceived patient experience ranged from the positive aspects of comfort and continence to the
23 negative of embarrassment and discomfort. Nurses were motivated by the medical need for
24 bowel care but often saw it as low priority due to the unpleasant nature displaying avoidance
25 tactics. The barriers concerned inadequate training, the taboo nature of bowel care and potential
26 sexual interpretations of care.

27 Conclusions: Nurses find bowel care unpleasant but accept its medical need and importance. The
28 normalisation of bowel care training and increasing numbers of nurses trained may decrease
29 stigma surrounding provision of care. This study highlights that a male nurses' experience may
30 differ from a female nurses' but this requires further investigation.

31 Sponsorship: No external funding.

32 Key words: #Neurogenic bowel #Spinal Cord Injury #Nursing experience #Bowel care

Introduction: Spinal cord injury (SCI) and resulting lack of coordination with the central nervous system changes gastrointestinal transit. SCI patients frequently lose rectal sensation and ability to defecate normally, termed neurogenic bowel (1). Most SCI patients require bowel care which can include digital rectal stimulation and digital removal of faeces. Patients and specialist nurses have described poor bowel care in SCI patients with devastating impacts on patient dignity and health (2). Nurses reportedly fear bowel care due to a misbelief it is illegal or that they can cause injury to patients (3). Gaps in practice surrounding continence and bowel care in all patient groups has been recognised as a national issue (4). The Royal College of Nursing (3, 5) has recognised an inadequacy of care provision surrounding digital rectal examination (DRE), lower bowel dysfunction, digital removal of faeces (DRF) and digital rectal stimulation (DRS). Despite repeated publishing of guidance and acknowledged gaps in practice no studies have explored the experience of acute nurses who provide bowel care and barriers to quality bowel care provision. Exploring the experience of nurses could help explain gaps in practice will help create a basis to develop an action plan to address issues.

Participants and Methods:

11 registered nurses from 3 ward areas in an UK NHS trauma centre who were deemed competent in provision of spinal bowel care by their current place of work were interviewed. Participants were all experienced in caring for acute stage spinal injury patients with length of experience ranging from 1-10 years with the majority having between 3-5 years (N=7) experience. 2 participants had prior experience caring for SCI patients in other settings and were the only participants who had previously provided SCI bowel care. Most were band 6 nurses (N=7) with the

minority of band 5 participants. The majority were female (N=8, participants F1-8) and worked in a trauma high dependency setting (N=7) with some intensive care nurses (N=4).

The sample was a convenience sample purposive in nature with nurses volunteering to participate. Only indirect means of recruitment were used namely posters and emails sent via a trust-based gatekeeper. Posters were placed in each ward area social space and emails were sent to all employed nurses in each area. The participant then contacted the researcher via email to avoid coercion, if a participant did not attend an interview one email follow up was sent before withdrawal was assumed. Participation was dependent on the nurse being declared as spinal bowel care competent by their current place of work. A list was provided by the research areas of competent nurses prior to the start of the study to ensure participant confidentiality. The numbers of staff nurses deemed bowel care competent was low taking into consideration the frequency of spinal cord injury patients and the acute nature of injuries. At the time the study commenced no staff nurses from the spinal and orthopaedic ward were deemed competent in bowel care. Overall 14% of the permanent nurse workforce in areas that receive SCI patients were deemed able to deliver bowel care.

Table 1 – Percentage of staff per ward deemed competent in providing bowel care to SCI patients

Semi-structured interviews were undertaken based on open ended questions and the audio was digitally recorded. The interviews were transcribed verbatim by the researcher and analysed thematically based on Braun and Clarke's (6) 6 stages. One interview was randomly selected using a computer number generator and the transcript was sent to the participant with codes attached

to ensure validity (member checking). Participants were given a unique identification number to ensure participant confidentiality, female participants we labelled with F whilst male with M and numbered sequentially.

Statement of Ethics: Ethical approval was obtained from the Psychiatry, Nursing and Midwifery Ethics Subcommittee of King's College London and from the NHS Trust specific Joint Research Compliance Office.

Findings:

Four major themes emerged: Unpleasantness of task, perceived patient experience, motivation and avoidance and barriers to care. Sub themes emerged in each of the themes:

Table 2 - Themes and Subthemes

Unpleasantness of task

Unpleasantness of task had sub-themes of: for nurse and perceived patient. The majority of nurses discussed the unpleasantness of task (N=9) largely in a stoic fashion. Handling faces was viewed as an integral aspect of nursing and as such the unpleasant nature for the nurse was accepted.

F1: "Its poo…I wouldn't have come into the nursing profession if I didn't have a strong stomach"

F7: "The smell, I hate it because of the smell and the whole process, I don't particularly like it, but I have to do it"

The unpleasant experience for patient was exacerbated by the acute nature of the injury and the new physically dependent state of the patient. There was widespread appreciation for the unpleasant nature of the care for the patient especially due to acute nature of injury.

F8: "Obviously they have just had a traumatic spinal cord injury so they tend to be quite fragile anyway and then they have someone emptying their bowel for them which is obviously not pleasant for them"

Perceived Patient Experience

Patient experience was very important to the nurses. They were well educated in the reasoning behind provision of bowel care. They understood the need for the bowel care and the comfort a good bowel motion could provide.

M3: "It is a need [bowel care]. The positive thing about it is you are able to relieve a patient. Make them feel…patients won't experience autonomic dysreflexia. Patients are more comfortable for daily living and also it trains the patients, trains the bowel for a certain time and certain bowel aids that they prefer to use."

Promotion of continence through good care was seen as an empowering factor for patients that allowed rehabilitation and improved quality of life.

M1: "There is also the possibility that they could become incontinent [without proper bowel care] which is obviously very unpleasant for them."

F5: "I think when it is instigated and it works well and their bowel is trained then it is brilliant as you can get them out during the day it doesn't interfere, having their bowel open, doesn't interfere with their rehab and things like that."

The negative patient experience was equally important. The experience of the patient had a direct impact on the experience the nurse took from it. Patients who were particularly young, embarrassed or had rectal sensation were viewed the most difficult patients for the nurses to provide care to. The invasive and nature of the care made the participants feel embarrassed on the patient's behalf.

F5: "I think that it can be quite embarrassing for the patient, I don't think they really like it, because often our patients are awake when we are doing it, and aware."

M2: "Its somebody's bum. Having to insert my finger somewhere I don't want to insert it. Umm Nine times out of ten when we are doing it the patients are awake and they are very aware of what we are doing and that makes me feel uncomfortable and it's the actual manual evacuation is just the worst thing that I can ever ever do and I have done a lot of weird things in nursing but that is the worst thing I have come across."

Privacy and dignity was difficulty to maintain during the care due to the acute setting and the time required to complete the procedure.

F8: "If the patient has a side room ideally. It's not nice for them to have to go through the indignity, as some may call it, and they are in a bay area or you have someone continually opening the door."

Gender and Sexuality

Gender and sexuality were raised as issues surrounding provision of bowel care by the male participants. The male nurses expressed concerns around caring for a patient of the opposite gender or having their actions perceived in a sexual nature. One male participant expressed their extreme hatred of providing the care and directly expressed reluctance in the insertion of a finger into a patient's rectum separating manual evacuation care from other nursing requirements such as suppository insertion.

M3: "On the first few weeks [female patient] would only prefer female staff to do [bowel care]. But in time she got used to it as part of her daily living she started to accept."

M1: "It [bowel care] is essentially an act of penetration, some people do it for fun…. I know that there is no sexual thrill what so ever in it for me, but I do worry that my patient might think that there is."

M2: "Every nurse has a weakness. For me it's the manual evacuation. I mean things like the enemas and the suppositories and doing the bowel check that's fine. But when it comes to that one part I just cave totally, I really struggle with that."

Motivation and Avoidance

In Self

The medical necessity as well as patient comfort provided the self-expressed motivation in the study. Few nurses expressed avoidance in themselves although one stated they have avoided the care in the past related to their confidence and one participant actively avoided the care provision as much as possible.

> *F2: "We have got to get it [bowel care] done because if we don't then they go dysreflexic and then you have a medical emergency on your hands"*

> *M2: "I absolutely hate it [bowel care] I would rather poke my eyes out. It's the only time I pull rank."*

Perceived in Colleagues

Avoidance in others was described largely related to avoiding training and therefore being unable to provide the care. The participants felt this was a purposeful avoidance, the nurses felt that their colleagues did not receive the training as they did not wish to provide bowel care. Work load on the participants was viewed as strained due to the avoidance of training by their colleagues.

> *F4: "I mean we get a lot of spinal cord injuries and saying that you don't have the training, isn't really good enough."*

Barriers to Care

Staffing/Skill Mix

Bowel care in the acute setting rarely requires only one healthcare professional, it can often requires at least one other to aid rolling the patient or even five, so the patient can be log rolled under spinal precautions. This represents a vast proportion of the nurses/healthcare professionals on ward. The first six months following injury are paramount to establishing an acceptable bowel regime (7), during the initial stages, the process can take extended periods of time to complete further straining the participants time to provide care. The lack of nurses trained as also highlighted as an issue. Often one nurse was providing bowel care for multiple individuals leaving nurses feeling stretched for time to care for other patients.

F5: "Staff constraints… getting people to help you roll."

M2: "Time. As with everything we do as nurses time. Very much depends on the skill mix and the work load on the unit."

F7: "At the moment not all nurses are able to do it. You are always getting dragged away, even if it's not your patient".

Training

Training was variable as no national or trust standard exists, variation was reported between participants trained in the same ward. Training varied from study days and presentations to informal discussions, all staff had competency assessments conducted on patients in their clinical areas. Sporadic admission of SCI patients and training teamed with a reported reluctance of staff to undertake this voluntary training was reported to lead to low numbers of trained nurses. The

training was not provided routinely was viewed as optional and specialised, this was perceived as a problem.

C1: "Maybe if they did it [training] more routinely as a band 5 like when you come onto the ward… you do like IV competencies, maybe in bowel care there was a competency linked to it."

F6: "More formal training probably would be better. A course would be better than someone coming in from the spinal unit to train you and then that's that."

*M2: "*So our patient's come through in groups so we can go a long period without having the spinal injuries and then suddenly we get a rush of spinal injuries so there's no real pattern to it."

Taboo

Bowel care was described as a taboo subject with participants who provide the care unwilling to openly discuss it. This left healthcare professionals unwilling to discuss the care even between themselves and are therefore unable to develop through professional discourse. A separation of the care from the normal tasks of nursing within departments was described. The perceived specialised nature of bowel care added to the taboo nature of the care as well as making care provision more difficult.

M1: "I guess probably the best start is to break down some of the barriers so that people are actually able to talk about it. And then we can learn from each other."

F4: "if more people are trained on it, then it's easier to find people and it will probably take the stigma away.. then it's not like a taboo subject."

Confidence and Competence

Variable training experiences resulted in differing views of competence verses confidence. A lack of formal competency assessments affected the nurses' confidence to provide the care. Assessment of competence was often undertaken on patients and a fear of damaging the patient or upsetting them at a delicate time of their acute injury was present. Assessments of competence varied from one supervised episode of bowel care to three. Some nurses felt this was insufficient and they expressed a feeling abandonment once assessed as they were left without another competent member of staff to guide them in the care provision. A lack of confidence resulted in avoidance of care provision.

F3: "I used to kind of shy away from it, but that was because I didn't feel really confident in doing it."

F7: "I had about 15 minutes theory and then she performed the procedure on the patient and then, that was it I was deemed competent."

Discussion

Bowel disturbances have a major impact on SCI patients and their emotional wellbeing as well as physical health (8). Bowel care in all patient populations is (9)under researched and although research has shown the importance of adequate bowel care to patients the experience of the healthcare professional is largely unknown (10, 11). The first six months of injury are crucial to develop good bowel routines and use of physical techniques are relied upon but are a challenging time of newly injured patients (12). Burns et al (9) interviewed support workers and spouses who

provide bowel care to SCI individuals around their views and experiences. These interviews showed similar findings to research in the nursing population, training remained a prevalent issue with support workers in fear of causing damage and feeling unprepared. The intimate nature of care was also highlighted with spouses and support workers alike finding the care provision uncomfortably intimate. The research by Burns differs from current research as there was no acceptance of the nature of working with faeces. Another crucial difference are there was no concerns regarding gender or sexual interpretations are care described. Differences in the reactions of patients who are in the acute rather than chronic phases of their injury may have influencing factors. Other influences may be due to the time the person providing the care has known the person they are caring for. Acute nurses often only know their patients for short periods of time whilst carers may be with their patients for many years. The support workers interestingly did discuss the difficulty in maintaining professional distance, which may again be a result of the time spent with the SCI individual.

The nurses accepted the unpleasant nature of bowel care however they separated it from other unpleasant nursing practices. Although the nurses interviewed understood the importance of bowel care the research suggests it was not always a care priority due to the invasive nature causing embarrassment to patient (perceived) and nurse alike. Continence is an integral aspect of adulthood in our culture, however failures in continence care were never as starkly evident as in the Francis report into the care failing in Mid Staffordshire hospital (13). If continence has a low priority it follows naturally that advanced continence measures would also be of a low priority. It however seems greater than a simple extension of the socially unacceptable nature of continence care. It extends into a taboo area for nurses and as such is met with resistance.

The fact that training in bowel care was specialist rather than a pre-requisite to working in an area that receives SCI patients is a factor in separating this care from standard nursing practice. Many of the nurses interviewed discussed the low numbers of nurses trained putting a burden of care on the nurses who are. They also thought that if all the nurses could give then care it may remove some of the stigma as it would become 'normal'. The perceived patient experience was very important to all the nurses interviewed. The unpleasant nature of the care for patients was a large determining factor for the nurses interviewed with avoidance of care when the patient was embarrassed. If the handling of faces which is socially unacceptable can be become normal within the profession, the normalisation of bowel care is theoretically feasible but it must be embraced as part of nursing.

Gender and sexuality due to the invasive nature of care was expressed by the male participants. This study is limited as only 3 male participants volunteered in the study so the data saturation is unlikely to have been reached. Nursing is traditionally a female dominated profession and stereotypes surrounding men within this workforce remain. Male nurses often feel vulnerable to accusations and misinterpretations of professional intimate touch (14). Male nurses being concerned about sexual interpretations of care has been described in other intimate aspects of care and when caring for female patients (15) directed training to better prepare male nurses could be beneficial (16).

Education of both nurses and patients will be important to the future provision of SCI neurogenic bowel care. The development of a national training framework may help reduce the variations in the training experiences described. There has been much debate surrounding the competency based training matrix specifically that it does not take into account the holistic nature of nursing (17). Training in bowel care needs to be more than an assessment of ability of complete the task and should include the emotional impact the care may produce. Addressing the potential negative experiences of patients during this care will be an integral aspect. Further research into the

experiences of nurses nationally will add to the body of knowledge and add to the transferability of the research.

Conclusion:

In conclusion nurses find bowel care unpleasant but accept faeces management as an integral aspect of the nursing profession. Manual evacuation and digital stimulation are separated in the nurses' view from other aspects of bowel care and are segregated from nursing care. Embarrassment on behalf of the patient due to the invasive and intimate nature of care are of concern. Inconsistent and often brief training that is specialist rather than an accepted norm of a spinal ward creates both a taboo aspect and increases the patient burden on the few trained staff. Further research into the impact of this intimate care on the male nursing population is required. Standardisation of training programmes should be investigated to see if greater confidence in bowel care provision can be instilled rather than simple competence assessment.

Limitations

The research was undertaken in the workplace of the principle researcher, who also conducted the interviews. This could lead to a limitation in the topics the participants were willing to discuss. Some participants may have been drawn to giving the perceived correct answer rather than expressing their own thoughts on the subject. The research was undertaken in an acute trauma centre and transferability of findings may be limited to similar institutions. The sample size was the expected size and is similar to comparable research, however there was a low number of male participants. The exact gender breakdown of the workforce was not known, however the areas were higher in percentage of male nurses than general ward areas. Further research into the male perspective is required as a difference in experience was described.

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Conflict of Interest

No conflict of interest to disclose.

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Tables

Table 1 – Percentage of staff per ward deemed competent in providing bowel care to SCI patients

Table 2 – Themes and Subthemes